

## ASD Stocktake of Resources

**Request:** Provide a summary of all the resources and tools that TAT use to inform decisions about Autism Spectrum Disorder (ASD).

A summary of recent AAT cases and TAT advice requests (planning and access) and a data capture of all ASD related matters identifies the recurring key issues relating to ASD that TAT provide advice for.

1. Data capture 2017-2019 ASD related advice requests
2. HPRM ASD case search
3. AAT cases specific to ASD (planning and access)
4. Data capture 2014-2019 ASD related AAT cases

The resources have been split into the following categories:

5. NDIA resources (legislation, guidance, SOP's)
6. Individual information specific to person
7. TAT published advice
8. Yammer groups for NDIS staff relating to ASD
9. Key research resources
10. IRABINA related resources

## Summary

The majority of referred to advices (1015 identified in the data table below) do not address autism beyond referencing that they are included (often as a co-presenting condition) among the participant's circumstances.

The vast majority of advices that the TAT research team were able to locate made no reference to any tools specific to Autism. In the majority, they refer to interpretation of legislation, or other internal instructions. Many are simply mandatory escalations to TAT regarding assistive technology for people whose complex circumstances include Autism.

The research team skimmed approximately 100/1015 identified ASD advices and consider the vast majority of advices reviewed not actually relevant to ASD. For example, these advices are about AT, communication, intellectual disability or other conditions and do not consider ASD specifically. The data simply reflects advices where ASD was one factor, not necessarily the primary issue being considered.

The most common request escalated related explicitly to Autism appears to be request for AT/communication devices for participants who are non-verbal. Most commonly an Apple tablet and associated accessories to support the communication application ProLoQuo2go. The only discussion regarding these requests appears to be the requirement for evidence of having trialed the devices, and the guidance to refer to base model devices rather than premium versions. The specific advice appears to be universal to communication devices for people with communication impairments and unrelated to Autism as a specific condition. The practice of trial before purchase, and use of base/'necessary' models rather than luxury models is effectively universal to assistive technology requests and is unrelated to Autism.

In cases where the question of access to the Scheme is raised, adequate evidence of diagnosis is the only discussion the TAT research team have been able to locate being referenced. The criteria to establish adequate evidence is not generally expanded upon within the advice, with the only specific example located indicating a brief discussion of not including diagnosis by a paediatrician. The advices the TAT research team have been able

to locate appear to predominantly refer to Autism as one of multiple conditions experienced by a participant being considered for access.

From the access escalations to TAT that the TAT research team have reviewed, it can be concluded that they reflect circumstances in which none of the participant's individual circumstances met access, and where the delegate has sought advice regarding the possibility that the sum capacity reduction of diverse circumstances may meet access.

Also, from informal conversations that the TAT research team has had with access delegates and advisors in the past that the guidelines for access to the scheme for participants with Autism are relatively clear and relate to the Autism CRC national guidelines and that a participant of the Scheme and require suitable evidence of diagnosis of ASD Level 2 or 3 under the criteria established in the DSM V.

The TAT research team have not yet located any access escalations to TAT where the evidence provided was clear and compliant with the CRC national guidelines. In cases where participants clearly have a disability level capacity reduction associated with Autism – the CRC guidelines are well understood by providers and closely match the established practices of providers in the sector. After analysis, the TAT research team have concluded that it would be relatively rare that a case containing ambiguous evidence would reach the TAT for advice.

## 1) DATA capture of ASD Advice Requests 2017 to 2019

**Key data capture from 2017-2019 where advice request lists ASD as primary disability.**

Theme	2017	2018	2019	Grand Total
Access - Initial Access			1	1
Access - Internal Review		3		3
Access - Other		2	1	3
Access - Revocation		6	2	8
Behavioural Supports / Psychosocial Disability	15	2		17
Capacity-Daily Activity	13	27	11	51
Capacity-Social, community & civic participation	3	5	1	9
Choice & control		2	1	3
Chronic Health Advice	4	15		19
Compensation	1			1
Complex AAT Reviews	3			3
Complex Assistive Technology	45	174	179	398
Complex Internal Reviews	9			9

Complex Physical Disability / Therapies	6			6
Consumables	1	3	6	10
Core-Daily activity	35	108	40	183
Core-Social, community & civic participation	1	9	3	13
Early Childhood	8			8
Employment	1	2		3
Functional Impact of Impairment	1			1
General R&N Advice	43			43
Health & Wellbeing		1		1
Home Modifications	32	39		71
Home Modifications-Complex		26	27	53
Home Modifications-SDA		26		26
Operational Policy Guidance	4	9	6	19
Other	1	1		2
Prosthetic & Orthotics	9	2	5	16
Relationships	3	2	2	7
Social, community & civic			1	1
Support Coordination	3			3
Transport	2	8	4	14
Vehicle Modifications	4	2	4	10
<b>Grand Total</b>	<b>247</b>	<b>474</b>	<b>294</b>	<b>1015</b>

	2017	2018	2019	Total
Autism	245	462	294	1001
Autism (secondary)	2	12		14
<b>Total</b>	<b>247</b>	<b>474</b>	<b>294</b>	<b>1015</b>

## 2) HPRM ASD case search

These 1000+ advices can be found through searching the TAT teams HPRM using the below search strings:

Title / Subject	Search String
AAT Actuary Report Autism Therapy 20180621	NED18/145609
Advices – Core Support	ADV + ASD + ADL
Advices – Restrictive Practices (behaviour support, ABA, other therapy interventions)	ADV + ASD + THER
Advices – Assistive Technology	ADV + ASD + AT
Advices – Home Modification	ADV + ASD + HMOD

### Specific HPRM advices that contain research docs

As mentioned above many of the 1015 TAT ASD advices identified as relating to ASD are not primarily about ASD. However during the skim review of 100 these two advices were isolated because they contain references to specific ASD resources.

**HPRM NED19/137843 - Adv 2018/7294** relates to an assistance animal for a participant with a service animal and provides some context and expansion around the decision that may be relevant to this review of resources.

It indicates that in March 2016 NDIA commissioned La Trobe University to review the evidence of effectiveness of assistance animals – see NDIA LTU Advice on Assistance dogs



ADV 2018 7294  
CORE assistance ani



NDIA LTU advice on  
assistance dogs.pdf

**HPRM – NED19/100608 - Adv 2018 / 7867** regarding ABA therapy for a 6 year old includes substantial research and several external links and resources.



ADV 2018 7867  
THER 20 hours per w

## 3) AAT Cases Specific to ASD

The historical/active cases have been split into access and planning.

### **Access:**

ASD matters we receive through the AAT for access:

- The TAT AAT access team have received a number (not sure exactly how many as there are a few advisors who work on the access cases) of applications from adults (over 40 and even in their 60's) who have had a fairly recent diagnosis of ASD Level 1. They are requesting access for assistance with social skills noting that they lack the ability to build and maintain relationships.
- The main argument used is that they have obviously always had ASD as this is not something you suddenly 'get'.
  - All the Applicants have finished their education, worked, married and had children prior to their diagnosis.
  - They have been able to manage their life, albeit some have had some difficulty with social interaction and communication, however, they do not meet the criteria of their impairment resulting in substantially reduced functional capacity.
- Many believe that simply having the diagnosis should grant them access to the Scheme.
- The TAT AAT access team also have adults being diagnosed with ASD because they have children with the diagnosis and then they are referred for assessment.
- The team have engaged independent occupational therapists to undertake a full functional assessment of the Applicant in their home to determine what difficulties they experience in the domain areas of Mobility, Learning, Communication, Social Interaction, Self-Management and Self-Care (these are the domain areas considered for access to the Scheme). They need to have substantial impact in one or more of these areas to meet access.
- As yet, the team have not had any assessment that supports the Applicant meets the threshold of substantially reduced functional capacity.
- The difficulties the TAT AAT team experience is that many health and allied health professionals are familiar with the wording used for a person to be granted access to the Scheme, particularly for early intervention. The team have identified some health/allied health professionals who note that the person requires intensive speech or psychological therapy to improve their current function and this would alleviate future disability support needs. If the person is an adult and there is no evidence of any intervention being completed in the past they may meet EI criteria for access. We have granted access in these instances.
- Another issue the TAT AAT team have identified is that many adults are not diagnosed using the DSM-V but rather the ADOS-2.
  - While the ADOS-2 is regarded by those who use it as 'gold standard', the severity level does not align with the DSM-V.
  - As List A notes a person with Level 2 or Level 3 ASD does not need to provide any evidence around the impact of their condition and would meet the access criteria, it is difficult to align an ASD diagnosis when no level of severity is provided if the diagnosis was made using the ADOS-2.

### **Planning:**

ASD matters we receive through the AAT for planning have the following key themes:

- Families of pre-schoolers and early school years age children with ASD requesting high level of therapy supports to pursue ABA.

- In many therapy has been delivered at high levels (greater than 20 hrs/week) for several years.
- These parents have often done their own research (or at times advised by the paediatrician) to determine that ABA is the 'gold' standard treatment.
- Early experiences of limited/no success with conventional therapy which often looks like individual SP perhaps with OT.
- Greatest number of requests for high levels of ABA proceeding to AAT coming from NSW.
- While centre based ABA therapy approaches exist in all states, in Victoria there are a number seeking funding for a 27hr/week program run by Autism Partnership. There may be an argument for this support for those children not able to manage in an Early Learning & Care (EL & C), but in most other situations the relative responsibilities of NDIS in terms of support and parent responsibility of funding EL & C opportunities is not clear.
- Overall limited evidence ECEI best practice in intervention with children and families with ASD.
  - Claims by ABA providers of following ECIA best practice in Early Childhood intervention National Guidelines when clearly they do not.
  - Provider reports often fuel parent expectations that more therapy is better and will overtime eliminate the delay between their children and others (no matter the severity of the ASD presentation)
- Parents and ABA providers using the reference to the recommended 20 hrs/week of early intervention referred to in Roberts and Williams 2016 to mean ABA therapy
- Parents not seeing/valuing the intervention they provide (often reinforced by providers saying parents needed to be parents) & providers breeding dependence by stressing skills need to be mastered with therapists before being 'generalised' by parents into other areas.

**The following AAT cases relating to ASD planning matters that resulted in published findings have been identified:**

Title	Date	Brief detail of decision	Link
TKCW and National Disability Insurance Agency [2014] AATA 501 (23 July 2014)	23-Jul-14	Intervention requirements - reasonable and necessary supports	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/501.html?context=1;query=National%20Disability%20Insurance%20Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/501.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>
ZNDV and National Disability Insurance Agency [2014] AATA 921 (25 November 2014)	25-Nov-14	Support not reasonable, relative to likely benefits ; To incorporate the terms of a further plan	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/921.html?context=1;query=National%20Disability%20Insurance%20Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2014/921.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>

McGarrigle and National Disability Insurance Agency [2016] AATA 498 (15 July 2016)	15-Jul-16	Not reasonable and necessary supports ; transport costs; taxis	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2016/498.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2016/498.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>
LJJY and National Disability Insurance Agency [2018] AATA 3506 (18 September 2018)	18-Sep-18	Not satisfied that it is a reasonable and necessary support; subsection 34(1)(c) and subsection 34(1)(d)	<a href="http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2018/3506.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA">http://www.austlii.edu.au/cgi-bin/viewdoc/au/cases/cth/AATA/2018/3506.html?context=1;query= National Disability Insurance Agency;mask_path=au/cases/cth/AATA</a>

#### 4) Data capture for AAT matters relating to participants with ASD (Asperger's and Autism)

There have been 334 AAT matters relating to participants with an ASD (Asperger's and Autism) during the 2014-2019 period. The increased number in AAT cases in 2018 likely reflects the timing of state and territory full scheme transitions, particularly SA.

##### Split by Year;

Year Received	AAT Matters Relating to ASDs
2014	5
2015	10
2016	19
2017	80
2018	208
2019	12
<b>Total</b>	<b>334</b>

##### Split by Age;

Age Range	AAT Matters Relating to ASDs
0-6	58
7-18	185
Adults	87
No Age Recorded	4
<b>Total</b>	<b>334</b>

##### Relating Exclusively to ASD (no other disability listed)

Disability	AAT Matters Relating to ASDs
ASD and other disability	56
ASD only	278
<b>Total</b>	<b>334</b>

Row Labels	AAT Matters Relating to ASDs
ASD and other disability	17%
ASD only	83%
<b>Total</b>	<b>100%</b>

## 5) NDIA resources (legislation, guidance, SOP's)

There are key pieces of legislation, practice guidance, operational guidance and SOP's that provide the overarching framework for all TAT access and planning advice.

NDIA resource	Link
Legislation	<a href="#">The National Disability Insurance Scheme Act 2013 (the NDIS Act)</a> <a href="#">The National Disability Insurance Scheme (Supports for Participants) Rules 2013 (the Supports for Participants Rules)</a> <a href="#">NDIS Restrictive Practice and Behavioural Support Rules 2018</a> <a href="#">NDIS (Supports for Participants) Rules 2013</a>
Practice Guide	<a href="#">Practice Guide – Intensive Super Intensive Participants.</a>
Standard Operating Procedures	<a href="#">SOP Behaviour Intervention Supports</a>
Scheme Actuary	Autism Therapy Support – Potential Impact on Scheme Financial Sustainability (June 2018)

## 6) Individual information specific to person

When TAT provide advice on access or planning decisions (including AAT cases), participant specific information is always considered. This is because advice is always given on a case by case basis. For example, clinical assessments, expert opinions, letters from medical or other health professionals will be considered.

## 7) TAT Published Advice

TAT publishes a list of de-identified, general advices on the TAT Digest page [NDIS Intranet](#). A recent tracking exercise has identified that the TAT Digest page is widely utilised across the agency as a key resource.

**There are eight TAT Published Digest relating to ASD:**

<b>Request title:</b> Funding of out of school hours care, 6 hours access to community on Saturday, 576 hours short term accommodation for a 10 year old.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/COPA%20ADL%20THER%20funding%20of%20access%20to%20community%20and%20short%20term%20accommodation%20for%20">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/COPA%20ADL%20THER%20funding%20of%20access%20to%20community%20and%20short%20term%20accommodation%20for%</a>
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	<a href="#">2010%20year%20old%20with%20autism%2020180514%20KRN451.pdf</a>
<b>Request title:</b> Review of high cost plans for twin brothers submitted for approval and determination of reasonable and necessary supports.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/layouts/15/WopiFrame.aspx?sourcedoc=/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201556%20%202016%201557%20BEH%20THER%20Review%20of%20high%20cost%20plan%20for%20twins%20with%20ASD%2020160227%20SH0031.pdf&amp;action=default">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/layouts/15/WopiFrame.aspx?sourcedoc=/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201556%20%202016%201557%20BEH%20THER%20Review%20of%20high%20cost%20plan%20for%20twins%20with%20ASD%2020160227%20SH0031.pdf&amp;action=default</a>
<b>Request title:</b> Assistance Animal for a child with Autism and Epilepsy	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/THER%20Empowerment%20Assistance%20Dog%20for%2018%20year%20old%20man%20with%20Autism%20SAP%20592.pdf">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/THER%20Empowerment%20Assistance%20Dog%20for%2018%20year%20old%20man%20with%20Autism%20SAP%20592.pdf</a>
<b>Request title:</b> Request for NDIS to fund Applied Behavioural Analysis (ABA) link therapy and Music Therapy for 10 year old child with Autism Spectrum Disorder (ASD).	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201112%20THER%20Requested%20supports%20fund%20Behaviour%20Analysis%20(ABA)%2010%20year%20old%20child%20with%20Autism%20(ASD)%2020170406%20KM0032.pdf?">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%201112%20THER%20Requested%20supports%20fund%20Behaviour%20Analysis%20(ABA)%2010%20year%20old%20child%20with%20Autism%20(ASD)%2020170406%20KM0032.pdf?</a>
<b>Request title:</b> AT - Freedom jogger pusher fitted with Pelvic strap, Rain canopy and Highback Kit.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Freedom%20stroller%20with%20accessories%20for%2010%20year%20old%20child%20with%20ASD%20and%20a%20Chromosomal%20disorder%20-%20201709%20MF0018.pdf">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Freedom%20stroller%20with%20accessories%20for%2010%20year%20old%20child%20with%20ASD%20and%20a%20Chromosomal%20disorder%20-%20201709%20MF0018.pdf</a>
<b>Request title:</b> Weighted Blanket for participant with Autism	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Weighted%20Blanket%20Autism%2020161107%20BSK479.pdf">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/AT%20Weighted%20Blanket%20Autism%2020161107%20BSK479.pdf</a>
<b>Request title:</b> Swimming and flexible respite/recreation/holiday care for a 6 year old with Autism.	<a href="https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%202529%20swimming%20and%20flexible%20respite-recreation-holiday%20care%20for%20a%206%20year%20old%20with%20Autism.pdf?">https://intranet.ndiastaff.ndia.gov.au/service-delivery/Technical-Advisory-Team/Documents/ADV%202016%202529%20swimming%20and%20flexible%20respite-recreation-holiday%20care%20for%20a%206%20year%20old%20with%20Autism.pdf?</a>


## 8) Yammer groups for NDIS staff relating to ASD

There are two Yammer groups for NDIS staff discussion that some TAT advisors use:

- [Autism Spectrum Disorders](#)
- [Understanding the Autism Spectrum by Dr Bennett, PHD](#)

## 9) Key research resources

The below resources have been frequently made reference to in advices or TAT advisors have indicated that these are key resources they make reference to.

- [Autism CRC](#) – Source of the Autism CRC National Guidelines
  - The TAT Research team has been advised that the CRC is frequently used by advisors for assessment/diagnosis for informal advices.
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Autism CRC  
National Guideline (
- [Raising Children – Autism](#) – An Australian parenting resource with an extensive series of Autism resources.
  - The TAT Research team has been advised that the raising children website is frequently used by advisors for best practice information.
- [Neurofeedback in autism spectrum disorder](#)
- [Early Intervention for Children with Autism Spectrum Disorders: ‘Guidelines for Good Practice’ 2012 \(DHS Australia\)](#)
- [Richard Simpson, Evidence-Based Practices and Students With Autism Spectrum Disorders](#)
- [Aspect Australia](#) – Australia’s largest service provider
- [Autism Advisory Board](#) – The national Autism peak body
- [Amaze Resources](#) – The Victorian Autism Peak Body’s resources page
- [Asia Pacific Autism Conference 2021](#) – A major conference scheduled for late 2021 that will likely be relevant in future.

## 10) IRABINA related resources

Information stated by IRABINA advises that *“IRABINA is Australia’s only Autism specific service provider for children and young people with the only severe behaviour program in the Asia Pacific Region. We will not turn anybody away and provide every Autism specific service. We can deliver services in your home, school, kindergarten or at one of our three sites across Melbourne”*.

IRABINA is a reputable provider of services for high end behaviour support / complex behaviour support for children with ASD.

Over the past year TAT have worked with Steph Gunn and IRABINA regarding best practice and costings for two specific participants requiring CSIR (TAT can provide names if required). These two participant cases demonstrate specific information about the IRABINA program and how TAT worked out funding advice.

One of the participant’s being discussed through CSIR with IRABINA was receiving supports through the ‘server behaviours program’. A summary of this IRABINA program can be found in this attachment.



IRABINA severe  
behaviours program

**Deb Clark – TAT Branch Manager is now the key Agency contact for IRABINA.**

There are general resources that can be found on the [IRABINA website](#).

IRABINA frequently provide additional supporting documents and clinical reports to enable NDIA reasonable and necessary decision making to be made.

The following are the advices directly related to IRABINA as the provider of high cost behavioural supports for children with ASD:

- Electronic Document NED18/197780
  - ADV 20182325 IR ADL THER HMOD request for home extension home modifications person to person supports and communication device child with autism behaviours of concern 20181017 KRN451
  - 15/10/2018 at 1:16 PM
- Electronic Document NED19/67206
  - ADV 20181281 ADL THER Core Supports and High Cost Severe Behaviour plan 2018.08.31 KRN451
  - 28/09/2018 at 2:23 PM
- Electronic Document NED18/223024
  - ADV 20182530 ADL THER One month review of high cost three month ABA intervention for a 12 year old with autism and severe intellectual disability 20181411 KRN451
  - 13/11/2018 at 3:11 PM